DRAFT

June 18, 2015

The Honorable Governor Brian Sandoval State Capitol 101 N. Carson Street Carson City, Nevada 89701

Dear Governor Sandoval:

As chairperson of the Nevada Commission on Autism Spectrum Disorders, I am writing to update you on the activities of the Commission, as required by Executive Order.

The Commission met with the representatives from state agencies, Legislators, parent advocacy groups, providers and other interested parties since our last report. We met as a group five times. The Department of Health & Human Services Aging and Disabilities Services Division website was updated to include all relevant information regarding the Commission and its activities.

We were pleased to see the urgency of addressing autism become a major budget initiative for the 2015-2017 biennium by the Governor as well as autism being mentioned in the State of the State address and then supported by Legislators.

The Commission's Five-Year Strategic Plan identified the followings goals:

- **Goal 1**: Maximize public and private funding sources to support the full scope of services needed for all Nevadans with ASD.
 - In 2015: Ensure Medicaid begins coverage for ABA; Address insurance barriers; Advocate for Maintenance of and/or increase to state and federal funding.
- **Goal 2**: Increase the system's capacity for diagnosis, treatment, services and supports for individuals with ASD across the lifespan.
 - In 2015: Policy in place which delivers immediate access to treatment and services based on failed autism screening.
- Goal 3: Expand the number and quality of professionals providing services
 In 2015: Track and fund statewide Registered Behavior Technician training.
- **Goal 4**: Promote a well-informed, empowered and supportive Nevada population around the issues of ASD.

Enclosed is an update on progress made on the recommendations from the Commission's Five-year Strategic Plan goals/objectives for 2015.

Nevada's Autism Statistics and Highlights reported to the Commission:

- √ 5,946 Students identified with an autism eligibility ages 3-21 attending Nevada schools (DOE, June 2015)
- √ 545 Children being served by the Autism Treatment Assistance Program (ATAP, 5/2015)
 - 28% are in the age range of 18 months to 5 years old; 30% 6 to 8 years old; 17% 9 to 10 years old; 25% 11 to 18 years old.
- ✓ 462 Children on ATAP's wait list (CLEO, 5/2015)
- ✓ 207 average number of days waiting on the ATAP wait list
- √ 58 new applicants to ATAP for the month of May 2015
- ✓ The children currently receiving autism funding from regional centers are aging out of their program. The Regional Center is now providing respite to children receiving ATAP.
- ✓ XX Children with ASD being served by NEIS (6/2015).
- ✓ Nevada Early Intervention (NEIS) indicates the average age at which a child is identified with ASD is 28 months. They have made a commitment to administer the ADOS (diagnostic tool) before children transition at 36 months and refer to ATAP.

A more in-depth report will be provided with the December Report to the Governor. As statistics are required to be reported in August 2015 pursuant to NV Rev Stat § 388.483 (2013). The Department of Education shall report annually to the Aging and Disability Services Division of the Department of Health and Human Services information relating to pupils with autism spectrum disorders; NV Rev Stat § 615.205 (2013). The Department shall report annually to the Aging and Disability Services Division of the Department of Health and Human Services information relating to persons with autism spectrum disorders who receive vocational rehabilitation services; NV Rev Stat § 442.760. The Early Intervention Services shall report annually to the Aging and Disability Services Division of the Department information relating to children with autism spectrum disorders.

The Commission is proud to recognize and applaud our state for the additional funding to address the needs of autism, funding to improve our education system and the legislation passed this session to support individuals with ASD and disabilities.

We believe our state has made great strides to improve access to treatment. However, there continues to be gaps in coverage and capacity to address the needs of all individuals across the lifespan and spectrum of ASD. Current concerns include:

- Managed Care and Medicaid's pending rates for the delivery of ABA and the effect of the provider pool and access to care.
- Medicaid's lack of coverage for evidence-based treatment specific to ASD (ABA) for individuals over the age of 21.

- Lack of transition services to address the specific needs of ASD population
- Limited access to research, supported amounts of evidence-based treatment
- Insufficient workforce and staffing issues for autism programs to meet needs
- Housing issues include: personal choice, availability, funding, lack of options specific to ASD
- Awareness about availability of services, where to go, how to obtain, how to pay
- Safety due to wandering, elopement with ASD population
- Lag between initial concerns, identification (failed screen and diagnosis) and access to research levels of evidence based treatment
- Disparities for critical populations rural/remote locations, racial/ethnic, low socioeconomic status. Lack of services and supports specific to adult ASD population which support self determination
- Lack of meaningful employment, pre-vocational and vocational training funding

We humbly ask and encourage you, Governor Sandoval, for an Executive Order to continue the Commission. The Commission is necessary to oversee the 5-year Strategic Plan and continue our work set forth in our by-laws. The Commission will have all five appointments expiring July 1. Three of the five Commissioners have indicated they wish to step down and allow new energy and ideas to inspire the Commission. Those three Commissioners are Keri Altig, school district representative; Mary Liveratti, member at large; and myself representing a parent/family member in the south. It has been an honor to serve since the beginning and it feels wonderful to know the foundation is in place to let go.

Thank you, Governor Sandoval, for your continued support of our community and for the extra help getting AB6 (insurance coverage for autism treatment) passed. We appreciate the valued support we receive from ADSD staff and your Chief of Staff. Because of your support, children with ASD have the hope of reaching their real potential.

If you have additional questions my contact information is (702) 595-2067 or comservjan@cox.net

With hope and gratitude,

Jan M. Crandy, Chair